Appendix 1

Preservation of Vision or Prevention of Blindness ?

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The mission of Ophthalmology has often been described as "Prevention of Blindness". Prevention of blindness certainly deserves our best efforts. Yet, the question has been raised whether this characterization is not too restrictive. The recent publication "Vision for the Future" outlines a Strategic Plan to "Preserve and Restore Vision". It was prepared by the International Council of Ophthalmology (ICO) and the Academia Ophthalmologica Internationalis (AOI) *(See the September editorial in this journal).* Likewise the World Health Organization (WHO) and the International Agency for the Prevention of Blindness (IAPB) chose as the motto for their current global campaign "Vision 2020 – the Right to Sight".

Prevention of Blindness and Preservation of Vision obviously go hand-in-hand. They are two sides of the same coin. There seems to be an evolving trend, however, regarding which side of the coin is presented first. Several reasons for this trend can be cited.

Epidemiological studies aimed at clarifying the prevalence of vision loss often run into difficulties because different groups define "blindness" in different ways. In the United States, for instance, it is estimated that 90% of the "legally blind" have residual vision. Hence, the old quote, which states, "More people are BLINDED by DEFINITION than by any other cause".

The term blindness has other problems. Eye care professionals must deal with all levels and degrees of vision loss, but the term blindness cannot be used with qualifiers such as "mild" or "moderate" blindness. How credible is a practitioner who tells patients with macular degeneration that they will never go blind, when the family brings a brochure from an authoritative source that lists macular degeneration as a "major cause of blindness"?

The word "blind" is used with the verb "to be", a verb that tends to label and categorize the subject. A statement like "You *are* blind" or "you *are* a problem" sounds definitive and invites the comment "There is nothing more we can do for you". "You *have* a visual impairment" or "you *have* a problem" leaves room for hope and invites the comment "What can we do to alleviate your problem?" The term "legal blindness" does not help either. It has been said that it is as preposterous to call someone with a severe vision loss *"legally blind"* as it would be to call someone with a severe heart ailment *"legally dead".*

The argument heard most often, in favor of the term blindness, is that it is such a good fundraiser. Yet, many agencies have changed their name from "Agency for the Blind" to "Agency for the Visually Impaired" or similar names. The two major projects cited in the first paragraph have joined this trend. I have not heard of any group or project that went back to the previous name. Would any of the projects that in the past have been billed as "Elimination of Avoidable Blindness" have been any less successful if they had been presented as "Elimination of Avoidable Vision Loss"?

A recent study of employment trends in the 1980s and 1990s suggests that legally blind individuals may not have benefited from improvements in the business cycle to the extent that other disabilities have. Could it be that the word blindness has worked against them, because employers are as scared of blindness as are individual patients?

There has been a move towards more standardized definitions. In the 1960's a WHO survey found that 65 different countries used almost as many different definitions of blindness. In the 1970's a WHO task force recommended to replace the dichotomous concept of blind vs. sighted with a series of ranges of vision loss that became part of ICD-9. The International Council extended these ranges to the range of normal vision, in which form they became part of ICD-9-CM, the official US Health Care classification. A recent review of epidemiological surveys showed that, two decades later, the major subdivisions have taken hold. Of the various surveys 95% reported on the WHO definition of Low Vision (< 6/18 or < 20/60) and on the WHO definition of blindness (< 3/60 or < 20/400).

In the past the focus of blindness surveys has mainly been on the CAUSES of vision loss. For this purpose the exact cut-off was not very important. The last half-century has seen a much increased interest in Vision Rehabilitation. – The first Low Vision Clinics were opened in New York in 1952. – Today, the focus of surveys is extended to the social and economic CONSEQUENCES of vision loss. These consequences begin to be felt long before the blindness level is reached. An Australian study found that fully one half of the elderly who presented with < 20/40 visual acuity could be brought to >= 20/40 (driving vision) by a simple refraction. The number of individuals with vision loss from under-corrected refractive error may thus equal or exceed the number suffering from cataracts and other causes traditionally associated with "Blindness". Even in evolving economies computer use and literacy are becoming much more important than they were half a century ago. Being a truck driver can be a major step up the economic ladder; loosing one's driver's license because of vision loss can be an economic disaster. While un-operated cataracts are still a major cause of severe vision loss, we are becoming more aware of the impact of less severe vision loss. Consequently we need to extend our surveys to levels that do not fit under the blindness label any longer.

What labels should be used instead? The generic term *Vision Loss* is applicable for a wide variety of situations and can be used with modifiers ranging from mild loss to total loss. Other terms may be used to refer to specific aspects of vision loss. The term *Visual Impairment* is appropriate when referring to a loss measured at the organ level. Visual Impairments include organ functions such as visual acuity loss, visual field loss, color vision loss, etc. (For congenital conditions the term defect or impairment is more appropriate than the word loss.) The term *Visual Dis-ability* has been used for the loss of visual abilities (reading ability, writing ability, orientation ability) measured as changes in the person's ability to perform certain daily living tasks. This aspect is also described by the term *Functional Vision*, to distinguish it from *Visual Functions* (acuity, field, etc.), which are components of the impairment aspect. The term *Visual Handicap* refers to the social and economic consequences of such an ability loss.

For each of these aspects, ranges of mild, moderate, severe, profound and total loss can be defined. Visual Impairment is the aspect that is most easily measured and quantified. It is the preferred measure for statistical surveys. However, two individuals with the same impairment may exhibit differences in their ability to cope with the demands of daily living. Visual Ability Loss, therefore, is the aspect that needs to be addressed in individual rehabilitation plans.

The International Council of Ophthalmology, in cooperation with the WHO, and in concert with its "Vision for the Future" and the "Vision 2020 – Right to Sight" project wants to promote more detailed reporting in vision loss surveys through wider use of the *Ranges of Vision Loss* that were first defined in the 70's. When using these ranges, the

term blindness should be reserved for those who are actually blind (total vision loss) or near-blind (near-total vision loss), i.e. for those who must rely primarily on vision substitution skills. For those with residual vision, i.e. those who can still benefit from vision enhancement aids, the ranges of mild, moderate, severe and profound vision loss or visual impairment are more appropriate.

Use of this terminology will not only benefit the profession through more accurate reporting; patients will benefit through the elimination of avoidable blindness labels that are unnecessarily threatening for those who actually have residual vision.